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AUTHOR	Whitney-Thomas, Jean; Timmons, Jaimie Ciulla
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ABSTRACT

This study examined the role and participation of facilitators, family members, and friends in the person centered planning process for youth with disabilities. It examined the participation of 10 youth (ages 18-21) with developmental disabilities who took part in Whole Life Planning processes through observation of 34 organizational and planning meetings and 17 interviews with the young people, their parents, and facilitators. The study identified eight factors that encouraged participation by the focus person including: speaking directly to or directing questions toward the focus person, speaking at the focus person's language level, and using accommodations as needed. Three factors that decreased participation were also identified: using jargon, using the third person, and using patronizing language. Also identified were three factors important for the group process: writing suggestions on flip charts, using good group facilitation skills, and actively involving the focus person in the group process. (DB)

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Jean Whitney-Thomas
Jaimie Ciulla Timmons

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by Jean Whitney-Thomas and Jaimie Ciulla Timmons

Introduction

The importance of self-determination for young people with disabilities has become an increasing priority for young people, families, and professionals. Person centered planning has emerged as one mechanism for young people to build self-determined futures with the help of a supportive group of people.

In general, person centered planning encourages an individual to involve personal and community networks in planning for the future. The process includes articulating a vision and coordinating resources and supports to make the vision a reality. Therefore, the effectiveness of planning depends on the support of significant others who assist in problem solving and resource development. Equally important in determining the success of a planning process is considering how facilitators, family members, and other members of the person's social network influence the focus person's participation.

This summary is meant as a resource for facilitators, family members and friends who are invited to be part of a person centered planning process. Recommendations are made to challenge planning team members to think about how their own behavior influences the participation of the focus person.

Methodology

This summary was developed from research conducted at the Institute for Community Inclusion between June 1996 and June 1997. The research examined student participation in Whole Life Planning and involved:

- Ten 18-21 year olds with developmental disabilities in four Massachusetts communities who participated in Whole Life Planning processes.
- These young people were from various cultural backgrounds (Latino (n=3), White (n=6) and Asian-American (n=1)).

The researchers:

- Observed 34 organizational and planning meetings.
- Conducted 17 interviews with the young people, their parents, and facilitators.

Findings

Factors that encouraged participation from the focus person:

- *Speaking directly to or directing questions toward the focus person.* This encourages the student to answer and discourages other participants from answering for them. This can be challenging for families from cultures in which an elder traditionally answers questions. In all situations, negotiate ways in which the focus person's voice can be heard.
- *Verifying* or checking with the focus person on the meaning of his or her answers, responses and suggestions before moving on. Make sure that he or she understands and agrees with the contributions of others. This creates an opportunity to draw the focus person back into the discussion if he or she becomes quiet or withdrawn.
- *Speaking at the focus person's language level.* By rephrasing words or concepts that were abstract, the focus person participates more productively and remain engaged in conversation.
- *Waiting for a response from the focus person.* When the facilitator allows the focus person time to formulate and produce an answer, other family members and friends are less likely to jump in, and the focus person is less likely to rely on them for answers.
- *Using accommodations* to support the focus person's understanding and communication. These include pictures, visual or auditory clues, technology, or any other concrete techniques that facilitate communication.
- *Following the focus person's lead* to change the subject, take a break or talk more about a topic.
- *Setting and maintaining a positive tone.* A positive tone can be maintained by reframing negative comments and addressing concerns in the establishment of action steps after the vision is completed.
- *Setting aside fears and concerns while the vision is developed.* When parents and others feel that their fears and concerns will be addressed during action planning the focus person can be encouraged to speak about their plans for the future and expand upon them during the building of the vision.

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Factors that decreased participation:

- *Using jargon.* Words or phrases that were unclear to the focus person.
- *Using the third person.* Speaking about the focus person to the group.
- *Using patronizing language.* Correcting or talking about the focus person in a way that causes the student to loose face or become embarrassed.

Factors that were important for the group process:

- *Writing suggestions* or statements made by group members on flip charts or meeting notes. This provides a visual record of the discussion, increases the amount of shared information, and reinforces group participation.
- *Using good group facilitation skills.* For example: setting and maintaining the group tone, not letting one person dominate, responding to the group as a whole, eliciting input from quiet participants, keeping track of time and taking breaks, and encouraging participants to speak directly to other members of the group.
- *Actively involving the focus person in the group process.* As the group process moves along participation opportunities for the focus person may be lost. Ways to insure the involvement of the focus person in the group process include: Using pictures instead of written notes and teaching the focus person group participation and leadership skills.

Conclusion

When asked to facilitate, organize, or participate in a person centered planning process, it is important to consider how to maximize the leadership of the focus person. The goal of any person centered planning process is to develop a clear vision for the future built on the hopes and dreams of the focus person and to determine the supports and steps necessary to achieve the vision. The role of the group participants is:

- To support and be a resource to the focus person.
- To express their genuine concern and a personal relationship with the focus person.
- To make sure that the plans and visions come from the focus person and reflect what he or she wants from life.
- In order to play these roles well, it is important for each member of a planning group to consider the following:
- Make sure the focus person drives the discussion and planning.
- Leave pre-conceived notions and expectations about the focus person's future at the door.
- Use multiple modes of communication throughout the planning process (written, pictures, objects, etc.).
- Help the focus person learn group process, decision making, and problem solving skills.

Maintaining a balance between one's own participation and the focus person's can be challenging. One set of parents in the study put it beautifully. The father said, "this has to come from Andrew." "I know," said Andrew's mother, "I'm trying so hard to sit on my hands!"

Resources

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